

**Delaware Health Care Commission End-of-Life Workgroup  
Summary of Public Comment on Draft Report  
March 2016**

| Summary of Comment  | Section |
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| Recognize that families and decision makers have vastly different abilities and backgrounds, and that some families will need more supports than others in order to provide adequate care for the dying person. In some cases, caregivers may not have the capacity to care for the dying person at home. There needs to be a system in place to identify the families needing extra support, and a means of providing closer monitoring of these patients.   | General |
| Definitions are glaringly missing: palliative care, hospice care, end of life care issues areas p.2..) Also, end of life vs actual dying or immediately (sic) dying are two different states of being and should be separated out for definition,   | General |
| Can someone opt out of these EOL discussions?   | General |
| Please state the DMOST form is NOT the only form that can be used as an advance directive by a patient and that Catholics have a right to a Catholic Directive.   | General |
| The report makes no mention of pediatric palliative care and the needs of children with life-shortening conditions.   | General |
| The report makes no mention of the Concurrent Care for Children Requirement, section 2302 of the Affordable Care Act, and how Delaware plans to educate patients, families and providers regarding what this provision allows for sick children under Delaware Medicaid.  | General |
| There is no mention of grief or bereavement resources in the state, especially for bereaved children for whom (sic)   | General |
| Ensure pediatric palliative care representation on the workgroup.   | General |
| I attended the public hearing in Seaford and thought the dialogue was excellent bringing up the concerns of many, in particular, of not using this report as a vehicle to further promote the cause of "physician assisted" suicide. While I wholeheartedly endorse expanding and clarifying the issues of "end-of-life" and palliative care through education, the role of government should not be expanded in anyway here. These are issues that should remain in the hands of the individual patient and their families. Again, although there is a disclaimer in the report that the issue of "physician assisted" suicide was not a part of the workgroup's charge, I would not want the results of this report laying the groundwork for any legislation on this issue. The government has enough on its plate now days than to be involved in issues that are between the patient, their families and God. I would like to thank the Workgroup and all those who participated in the public sessions for their efforts and thoughts on this matter. | General |
| <p>During the course of my treatments, there were times when I needed assistance with certain palliative care, but didn't know where to turn.</p> <p>The Governor's Advisory Council for Exceptional Citizens (GACEC) created a web site called the Delaware Disability Hub. It is a one-stop source that is easy to navigate and obtain information on disability services, providers and supports. <a href="http://www.deldhub.com/">http://www.deldhub.com/</a></p> <p>My recommendation to your Workgroup is to create a similar site around palliative care and end of life issues. It is frustrating to learn about a resource after the time has passed that you actually needed it. A site such as this, listing "who does what" could help us bypass sifting through information and allow us to access exactly what we need in a timely</p>   | General |

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| manner. In addition, given HIPAA regulations, it could help family members access information on services available vs. trying to get info from the patient's physician.  |         |
| I hope palliative care gets integrated early into cancer (and other) patients' therapies.   | General |
| In any definition of palliative care consider including that palliative care intends to neither hasten or postpone death. Specifying that palliative care intends neither to hasten or postpone death will prevent any possible confusion between it and assisted suicide.  | I       |
| Clearly define and differentiate between palliative, hospice and end-of-life care. These definitions are needed since they are not already included in the report.  | I       |
| Seriously ill and terminally ill are not one in the same as per p. 2 line 4. Seriously ill persons have recovered if given proper medical care, nutrition, and hydration.   | I       |
| Comprehensive health care services is not defined p.2   | I       |
| Regarding #3 on the top of page 5: I recommend adding language consistent with “and performing other healthcare tasks” at the end of the sentence. The medication issue is certainly a critical issue, but there are also policies which may prohibit home care providers from providing other healthcare tasks (e.g. wound care, catheter care, etc.). There was a bill passed in 2004 which attempted to help with this issue, but we find that many home care providers and attendants still do not provide services in these contexts.  | II      |
| Risks and Benefits p 6. second paragraph- This needs further explanation since it implies that someone else is going to set limits on what care can be delivered. This needs a great deal of refinement to assure the patient he/or she may choose a risk with little benefit since they may want to live irregardless of a risk benefit evidenced based formula.   | III     |
| In the definition of palliative care please state unequivocally that a patient will receive nutrition and hydration since this is understood in comprehensive health care services.   | III     |
| Please define adequate pain relief vs deep sleep sedation. The public should be adequately informed about the different levels of pain relief used in palliative care.  | III     |
| Request to include Wilmington University on page nine under organizational affiliation to acknowledge the educational piece that the University has in place for the health care providers.   | IV      |
| 2 areas of educational focus: 1 is in the outpatient office with PCP and specialists as this training is the most valuable. The second is for hospital based providers. This training might look different for Hospitalists, Intensivists and others who do not have an outpatient practice. In both cases, may I suggest we engage the fantastic minds we have across the state (maybe through the medical society) to come up with the standards and a training program that Hospitals, ACOs, and other networks could utilize for training. I am afraid that if we use DCHI, the training will be late in the game. There is so much for DCHI to work out just to get our workforce up to speed that adding items to their agenda might not be a good idea for the short term. Long term, it is a good idea but I would recommend first using all the other options. | V       |
| I also think the idea of having a Data resource to capture someone’s Advanced Directive is insightful. Maybe the DHIN could help if they develop a patient portal.  | V       |
| Specify/define what the BRFSS is.   | V       |
| In all fairness some of the groups mentioned have been associated in the past with the Hemlock society and evolved with name changes and the public should be aware of this i.e. 'Compassion and Choices".p.14  | V       |

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| <p>No reference is made to anatomical donation. Organ, tissue and eye donation is a critical end-of-life planning topic. Unfortunately, many individuals who seek palliative care have the misconception that they are too old or too sick to make an anatomical donation, which may not be the case. Incorporating anatomical donation into the public awareness and educational components of this report would help to ensure those individuals are apprised of all of their options.</p>   | V        |
| <p>The report does not make clinical recommendations. There are some issues that arise regarding end-of-life care that may benefit from the guidance of this workgroup.</p> <ul style="list-style-type: none"> <li>a. Instances where the next-of-kin disagrees (with each other or the patient's directive) with an end-of-life decision in an acute clinical setting.</li> <li>b. Instances where two end-of-life decisions are or appear to be in conflict with each other. For example, a registered organ donor also has an EOL document that would appear to preclude organ donation.</li> </ul> <p>Often these circumstances can be reconciled. The workgroup has an opportunity to address these concerns as they occur today, as well as to address potential conflicts in systems such as that proposed by Senator Coons. The workgroup can ensure that these processes seek to preempt potential conflicts and that, where they occur, a mechanism for resolution is addressed.</p> | V        |
| <p>Offer resources for pediatric patients or their families in the annotated bibliography of resources.</p>  | Appendix |
| <p>Concern regarding general practitioners being permitted to practice palliative care, especially if they have limited knowledge of palliative medicine.</p>  | n/a      |
| <p>I think that there needs to be an emergency procedure in place to remove a health proxy who is not competent.</p>   | n/a      |
| <p>I think that when hospice receives a call stating that a patient is suffering, a nurse should be sent out immediately.</p>  | n/a      |
| <p>It seems to me that the primary purpose of the law should be to protect the dying person. There must be a way to better monitor the dying person's care, and to swiftly investigate family member's concerns.</p>   | n/a      |
| <p>Sadly, or predictably, my comments about too much government intrusion in health care decision making were omitted. I guess "listening" really means telling me what to think. Yes, I do have an "agenda", as does the State of Delaware. I want government bearcats out of my life, while they insist on meddling with it.</p>   | n/a      |